

University of Dundee

Drawing from our Experience

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DRAWING FROM OUR EXPERIENCE

STORIES OF TRAVELLING WITH DEMENTIA

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 Go Upstream

UNiVERSE
UNIVERSITY OF DUNDEE

DRAWING FROM OUR EXPERIENCE

STORIES OF TRAVELLING WITH DEMENTIA

About ‘Drawing from Our Experience’

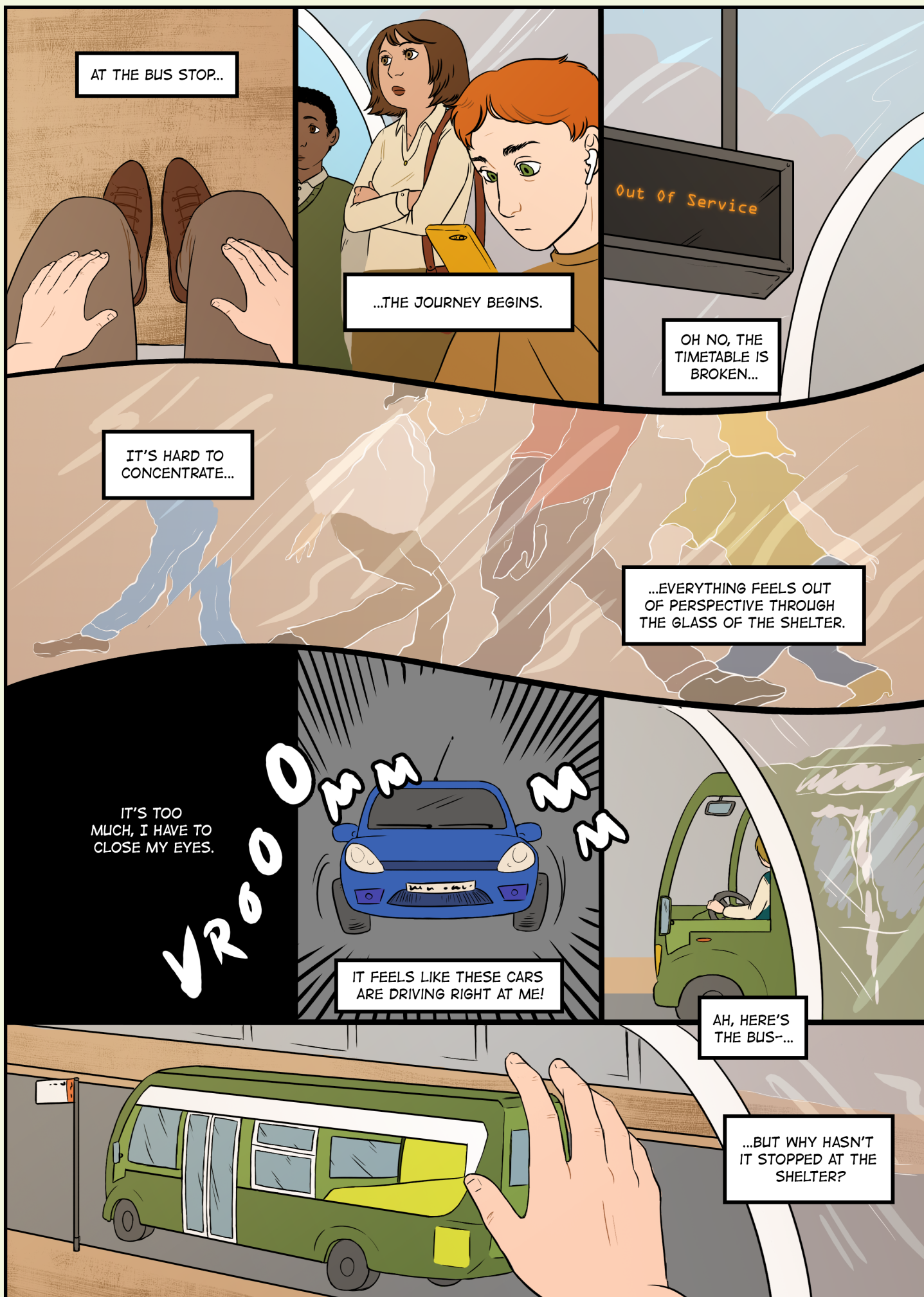
Getting out and about is essential to our wellbeing, particularly after a diagnosis of dementia. We all have a right to remain connected and active in our communities and yet many people affected by dementia describe difficult journeys and travel experiences.

Go Upstream works with people with dementia and service providers, bringing people together to create a shared understanding of travel challenges and potential solutions. This work has highlighted the emotional impact of the challenges that journeys can bring. We see that journeys aren’t just about the transport but about the plans we make, the people we meet, the services we use, the environments we travel through and the destinations we visit.

One of Go Upstream’s aims is to help service provider staff to truly understand the experience of travelling with dementia in order to support service improvement, ideally by travelling with people with dementia, gaining insights into the real challenges. But what if staff can’t be there? How do we tell stories that truly describe the experiences that some people with dementia may have?

We wondered if using the combination of artwork and text in a comic format might begin to tell these stories. If artists and people with dementia travelled and created artwork together, could we begin to more accurately describe the sights, sounds and experiences of a journey as experienced by someone living with dementia? Could we highlight the sensory impacts of dementia? Would the resulting comic be useful as a training resource, helping staff to understand the impacts of services and environments on passengers? Would the format be more accessible for people with dementia?

We started to explore these questions as part of the Drawing from Experience project funded by a Disruption Award from the Dementia Services Development Trust. After taking journeys together, artists and people living with dementia developed these stories to describe particular challenges. Of course, these can’t represent everybody’s experiences but we hope that this work can start conversations about how we can begin to design better journeys.



AT THE BUS STOP...

...THE JOURNEY BEGINS.

Out of Service

OH NO, THE
TIMETABLE IS
BROKEN...

IT'S HARD TO
CONCENTRATE...

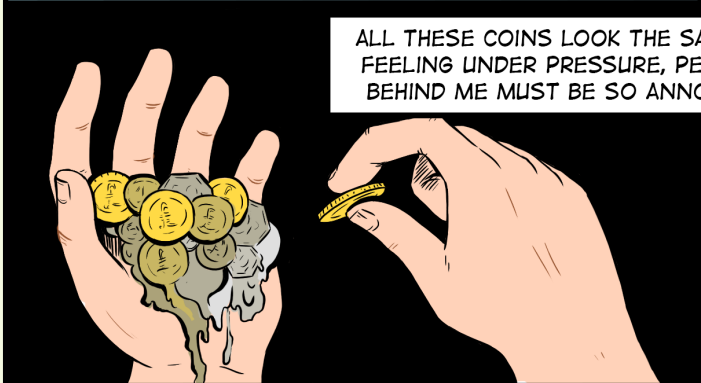
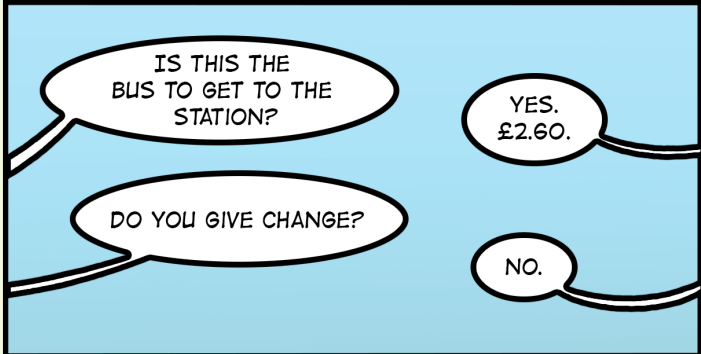
...EVERYTHING FEELS OUT
OF PERSPECTIVE THROUGH
THE GLASS OF THE SHELTER.

IT'S TOO
MUCH, I HAVE TO
CLOSE MY EYES.

IT FEELS LIKE THESE CARS
ARE DRIVING RIGHT AT ME!

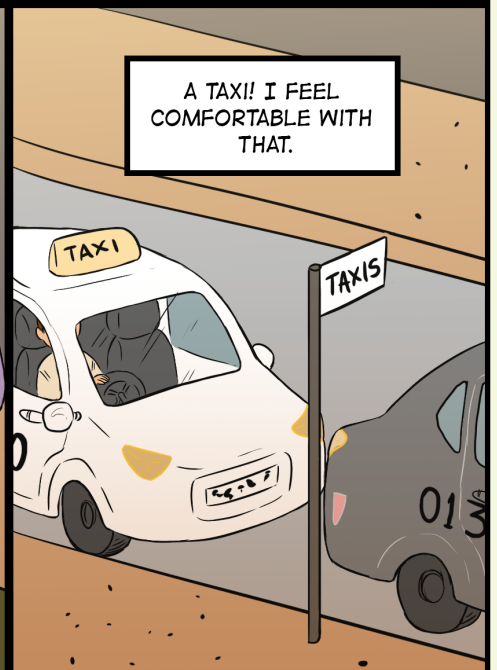
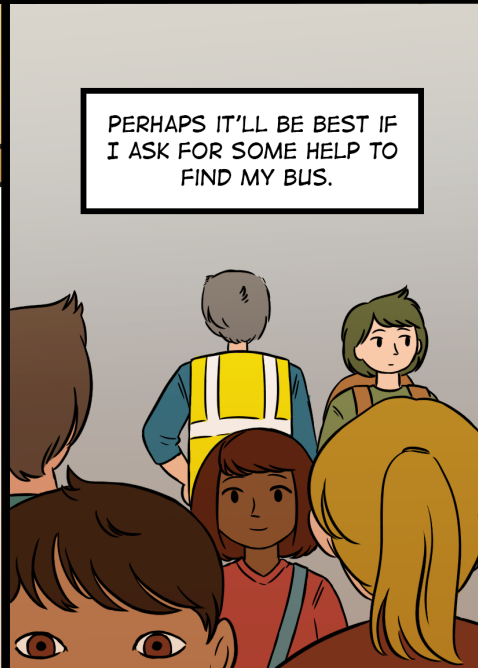
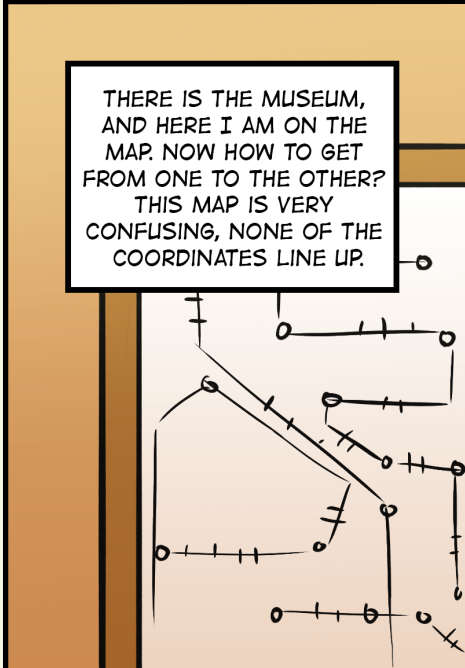
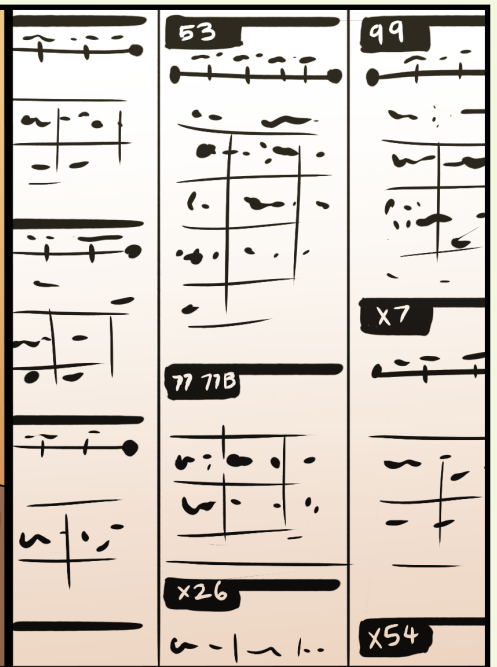
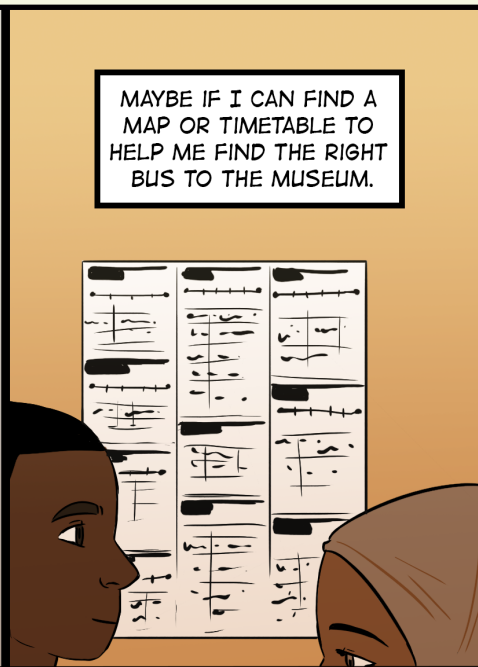
AH, HERE'S
THE BUS-...

...BUT WHY HASN'T
IT STOPPED AT THE
SHELTER?

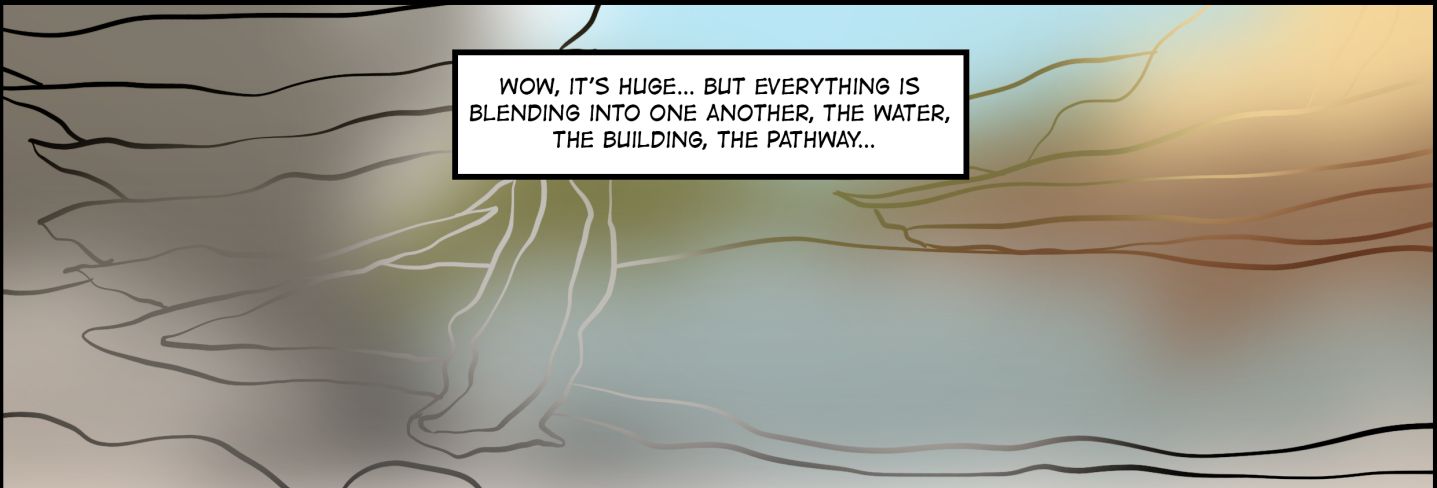


SENSORY OVERLOAD...
DEEP BREATHS...








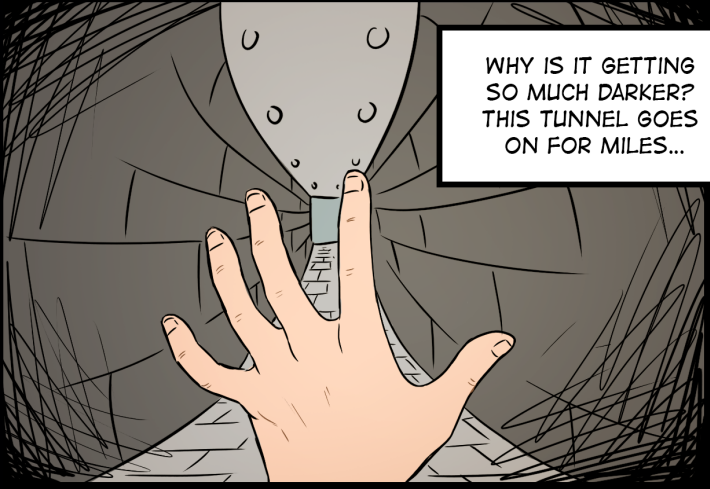


WOW, IT'S HUGE... BUT EVERYTHING IS
BLENDING INTO ONE ANOTHER, THE WATER,
THE BUILDING, THE PATHWAY...

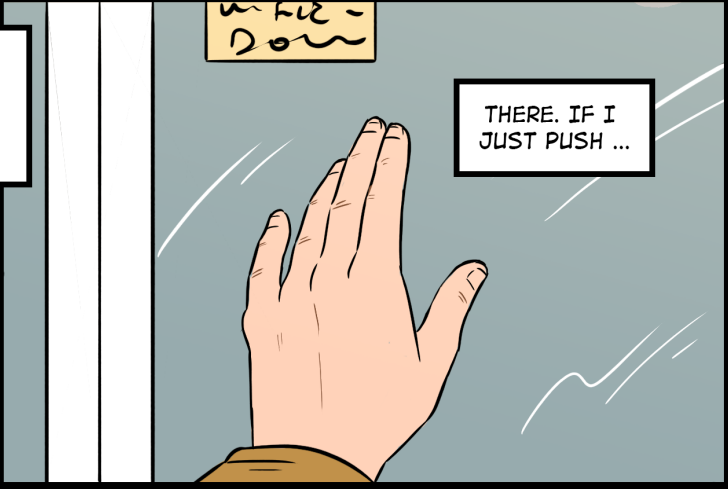


IT FEELS LIKE
THE PATH IS GETTING
NARROWER...

...DEEP BREATHS. I'M SURE IT
WILL BE BETTER INSIDE...



WHY IS IT GETTING
SO MUCH DARKER?
THIS TUNNEL GOES
ON FOR MILES...



THERE. IF I
JUST PUSH ...

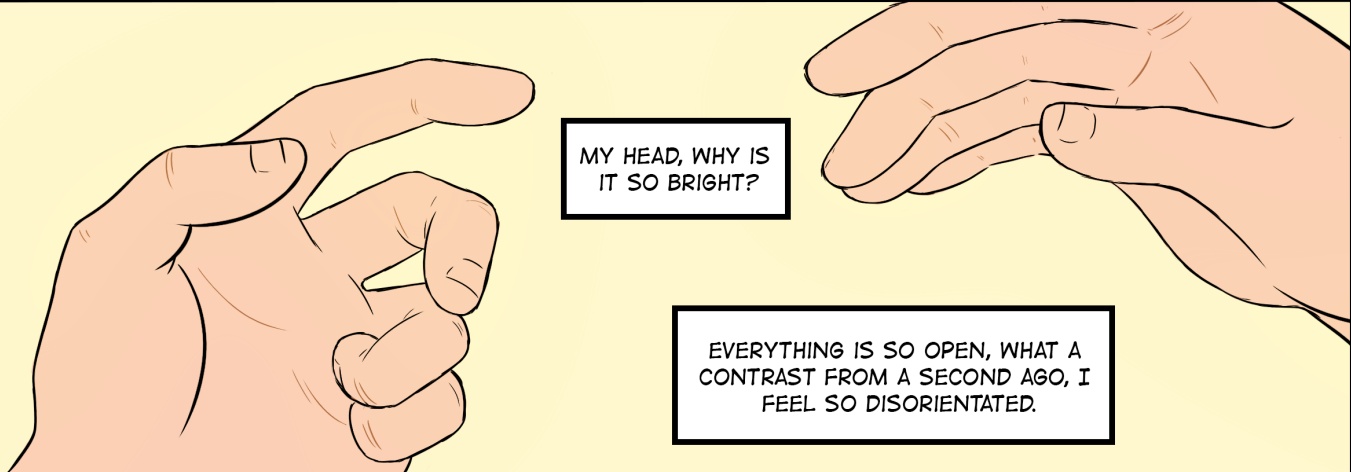


NO HANDLES

IT OPENED BY ITSELF,
I FEEL OFF BALANCE

IF I CAN JUST GET OUT
OF THIS DARKNESS AND
INTO SOME...

LIGHT.

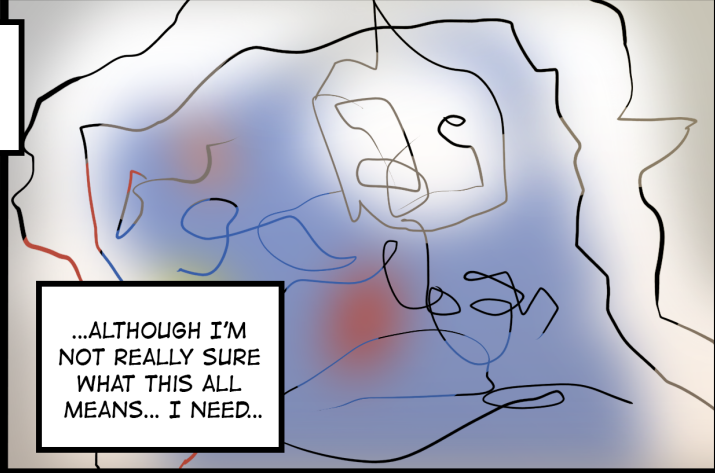


MY HEAD, WHY IS IT SO BRIGHT?

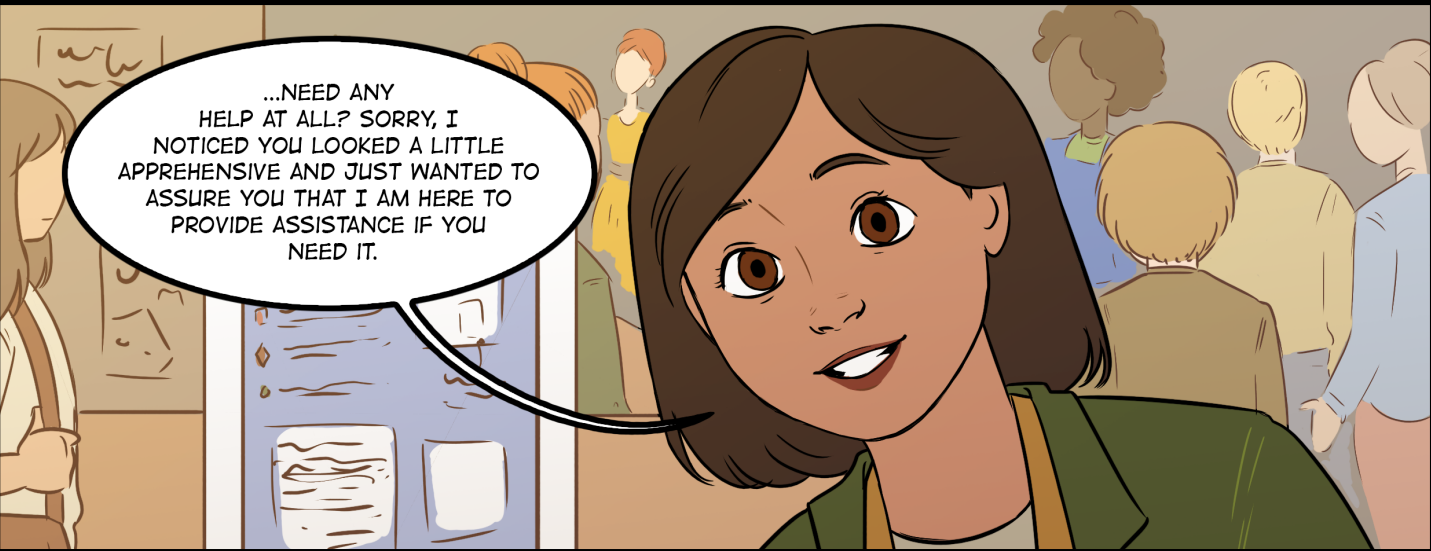
EVERYTHING IS SO OPEN, WHAT A CONTRAST FROM A SECOND AGO, I FEEL SO DISORIENTATED.



A MAP - I'LL JUST GET MY BEARINGS...



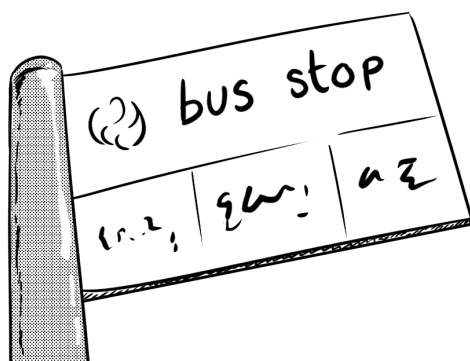
...ALTHOUGH I'M NOT REALLY SURE WHAT THIS ALL MEANS... I NEED...



...NEED ANY HELP AT ALL? SORRY, I NOTICED YOU LOOKED A LITTLE APPREHENSIVE AND JUST WANTED TO ASSURE YOU THAT I AM HERE TO PROVIDE ASSISTANCE IF YOU NEED IT.

THE END

THE START OF MY ADVENTURE.
APPARENTLY THIS BUS TAKES ME
STRAIGHT TO THE MUSEUM...



I'M LOOKING
FORWARD TO
THE DAY.

THE BUS DRIVER MUST
HAVE SEEN MY STICK AND
LOWERED THE STEP.

IT MAKES SUCH
A DIFFERENCE.

HI, I'D LIKE TO GET TO
THE MUSEUM. COULD YOU PLEASE
LET ME KNOW WHEN I AM
TO GET OFF?

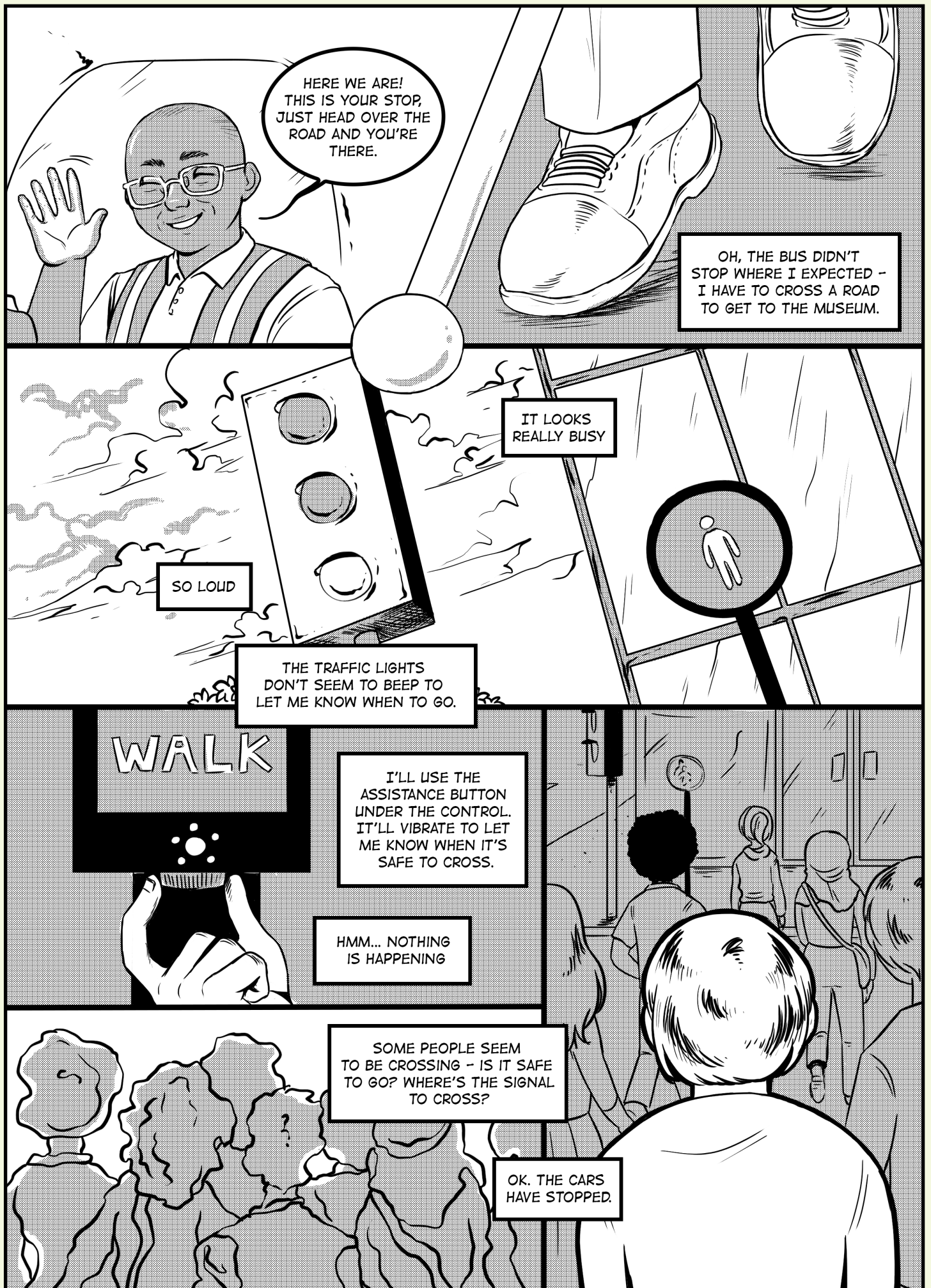
OF
COURSE.

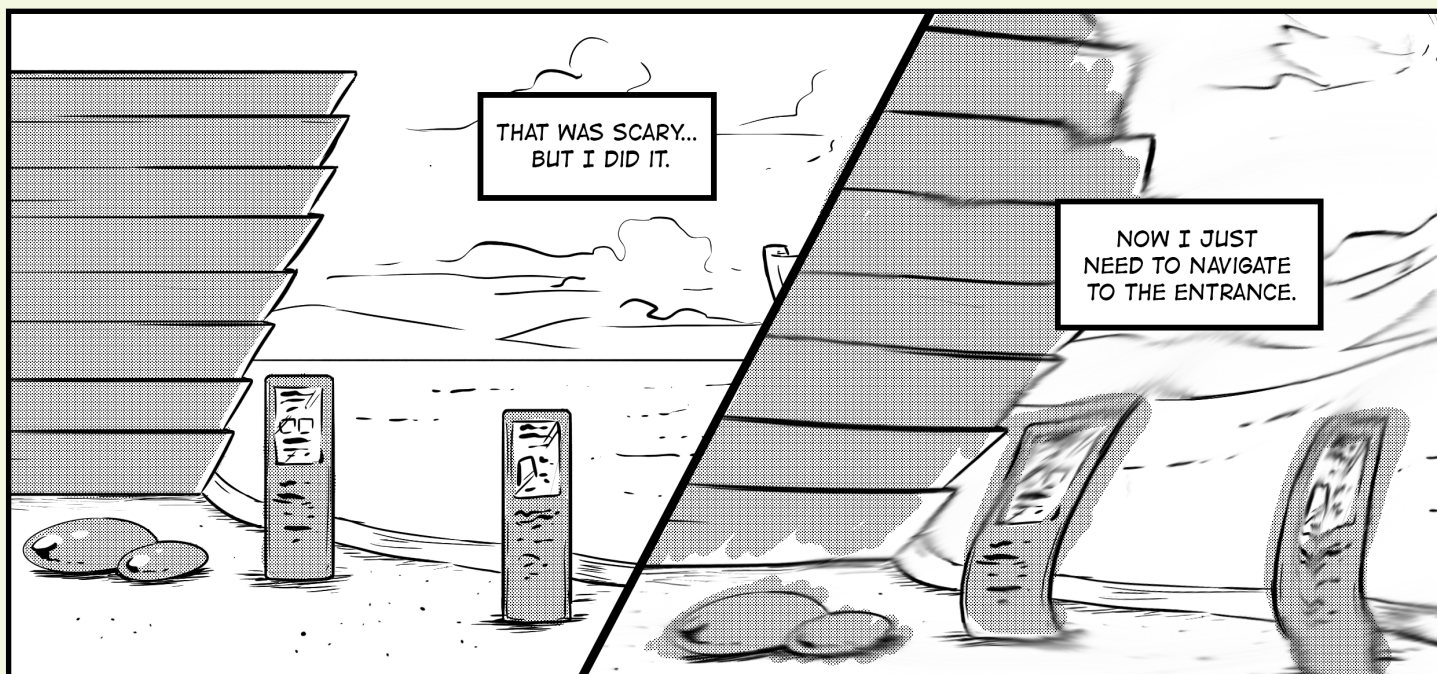
SO FAR SO GOOD.
NOW TO FIND A SEAT
AND RELAX A LITTLE.

THE CITY LOOKS LOVELY...

...AND THERE'S THE MUSEUM...

WAIT, WE WENT RIGHT
PAST IT! DID THE DRIVER
FORGET?



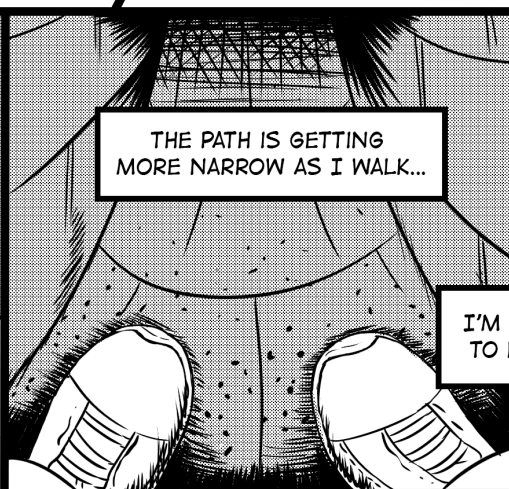


THAT WAS SCARY...
BUT I DID IT.

NOW I JUST
NEED TO NAVIGATE
TO THE ENTRANCE.



IS THAT PAVEMENT
OR WATER?



THE PATH IS GETTING
MORE NARROW AS I WALK...

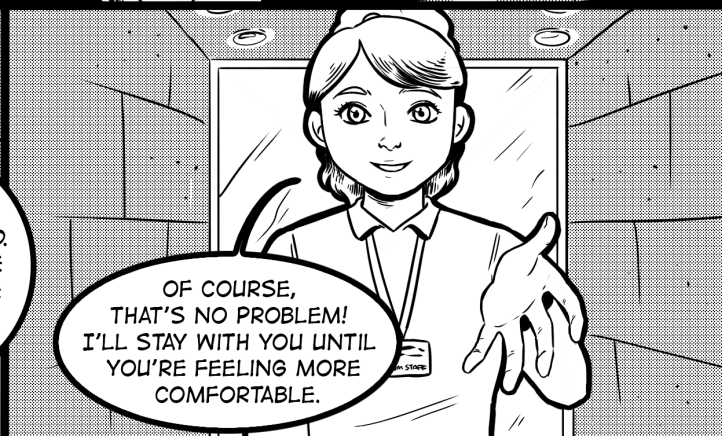


I'M SCARED I'M GOING
TO LOSE MY BALANCE.

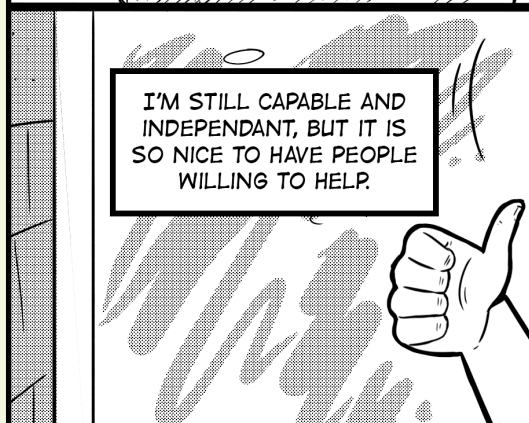


ARE YOU OKAY? YOU
SEEMED A LITTLE FLUSTERED.

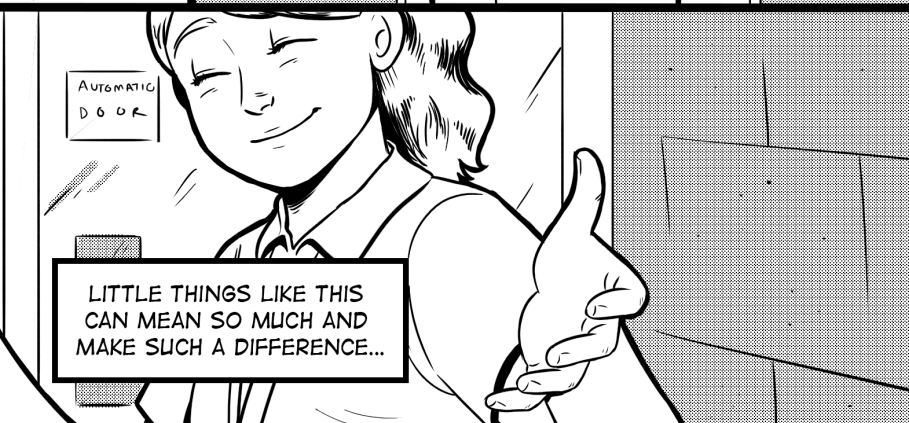
NO, I
AM A LITTLE
OVERWHELMED.
WOULD YOU BE
ABLE TO GUIDE
ME INSIDE
PLEASE?



OF COURSE,
THAT'S NO PROBLEM!
I'LL STAY WITH YOU UNTIL
YOU'RE FEELING MORE
COMFORTABLE.



I'M STILL CAPABLE AND
INDEPENDANT, BUT IT IS
SO NICE TO HAVE PEOPLE
WILLING TO HELP.

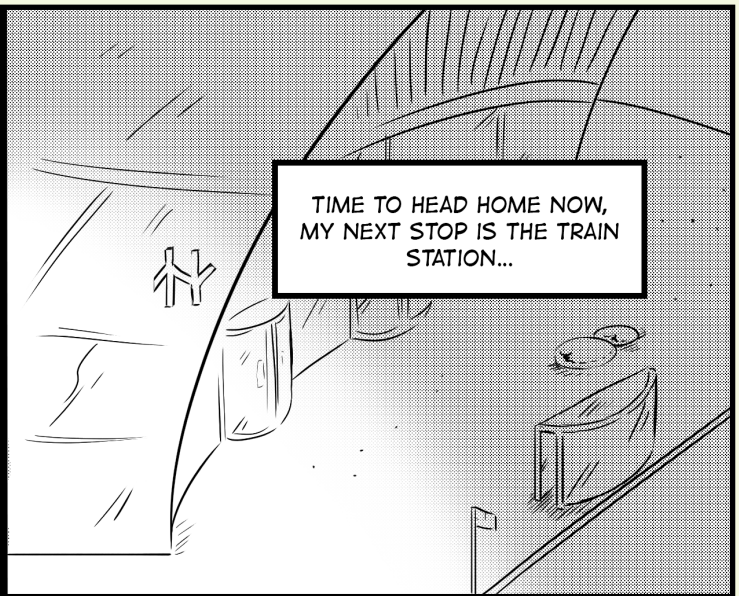


AUTOMATIC
DOOR

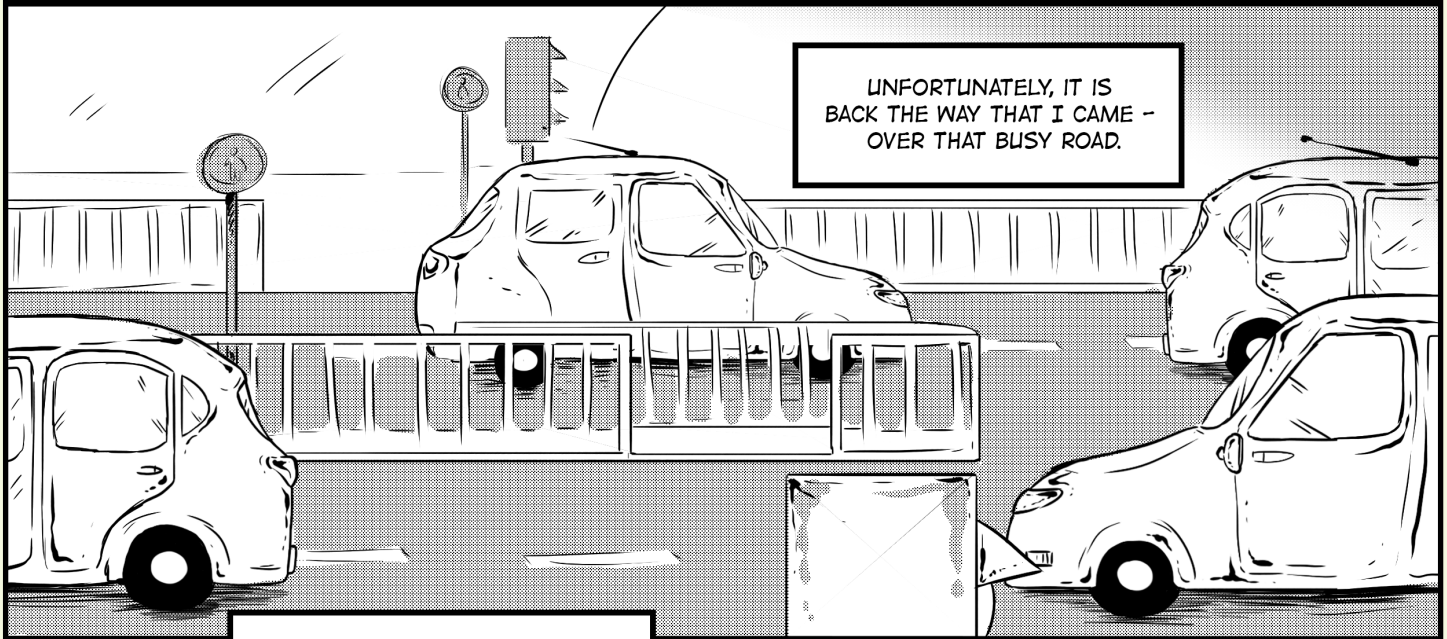
LITTLE THINGS LIKE THIS
CAN MEAN SO MUCH AND
MAKE SUCH A DIFFERENCE...



I'M GLAD I WENT,
THE MUSEUM WAS REALLY
INTERESTING. ALTHOUGH SOME
PARTS WERE DIFFICULT FOR ME,
EVERYONE WAS VERY KIND AND
ACCOMODATING.



TIME TO HEAD HOME NOW,
MY NEXT STOP IS THE TRAIN
STATION...

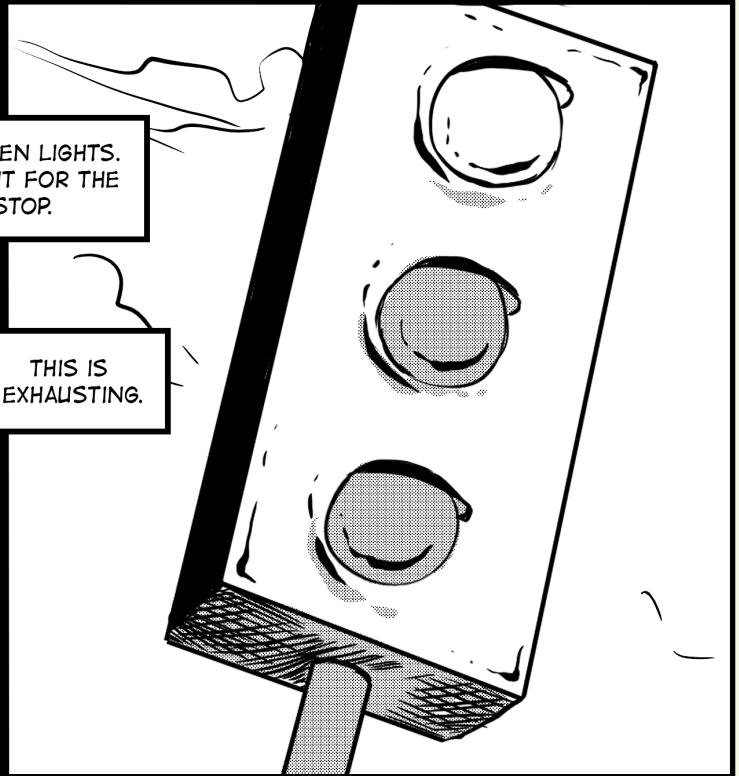


UNFORTUNATELY, IT IS
BACK THE WAY THAT I CAME -
OVER THAT BUSY ROAD.



IT'S LOUD AND BUSY AGAIN.
WHERE'S THE SIGNAL TO CROSS?

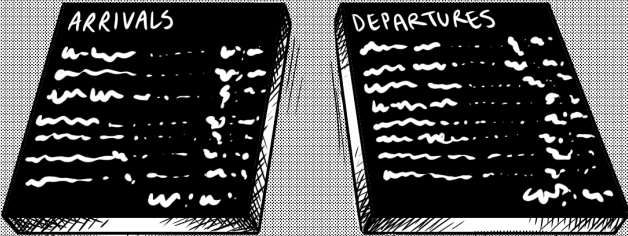
RED LIGHTS, GREEN LIGHTS.
NO BEEPING. WAIT FOR THE
CARS TO STOP.




THIS IS
EXHAUSTING.



AT LAST, THE
RAILWAY STATION.



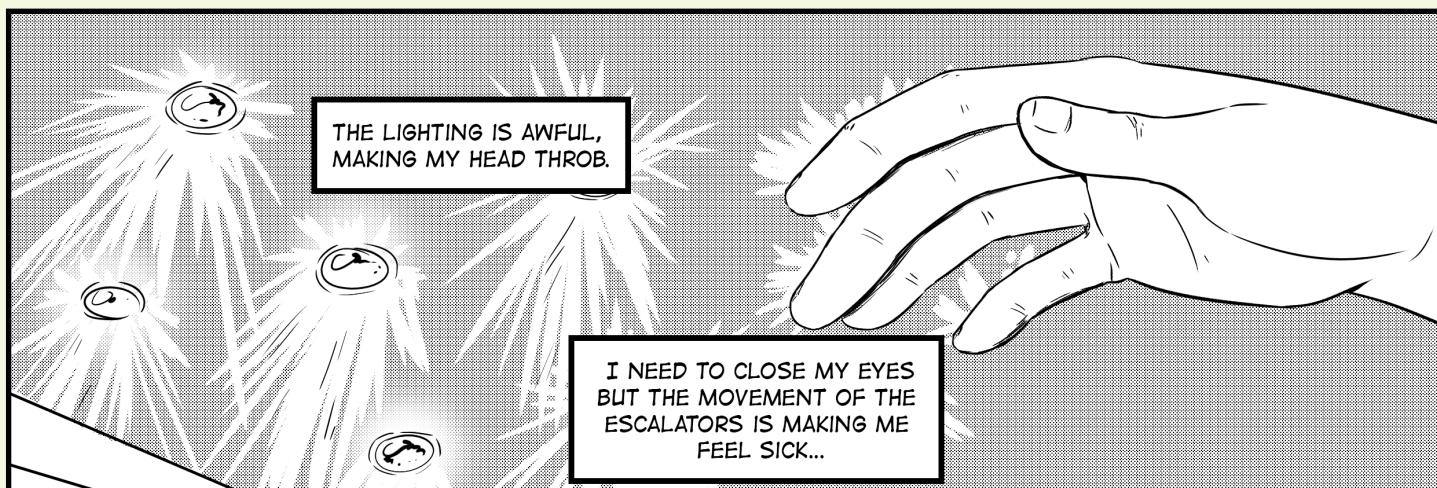
MY HEAD HURTS, AND THESE
SCREENS ARE CONFUSING. ARE THOSE
TRAINS LEAVING OR ARRIVING?



I THINK I'VE WORKED OUT
THE NEXT TRAIN BUT WHERE DO I
GO? NO SIGNS-



-...TO GO DOWN.
OH NO, ESCALATORS...



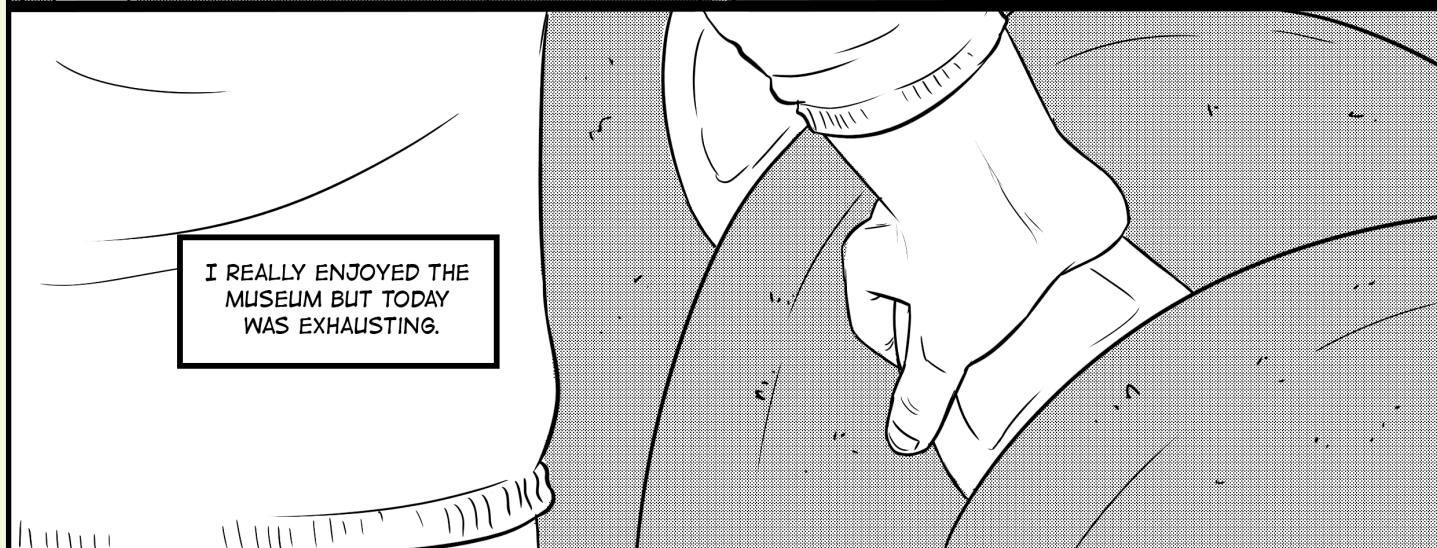
THE LIGHTING IS AWFUL,
MAKING MY HEAD THROB.

I NEED TO CLOSE MY EYES
BUT THE MOVEMENT OF THE
ESCALATORS IS MAKING ME
FEEL SICK...

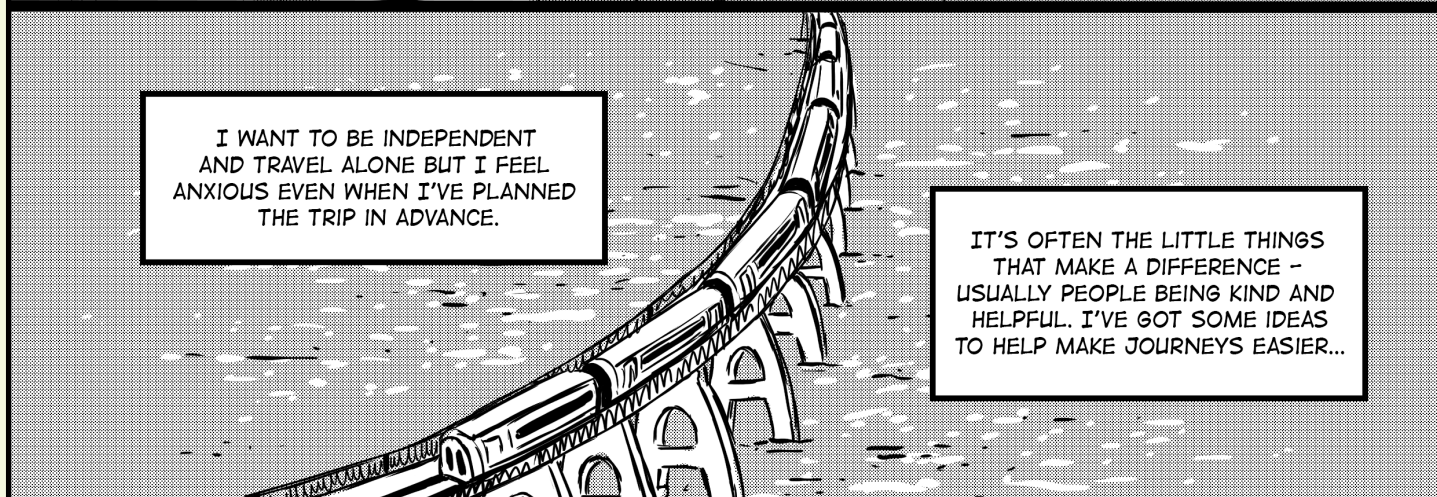


MY TRAIN SHOULD
BE HERE ANY SECOND.
I NEED TO HURRY.

WHERE DO I PUT
THE TICKET?



I REALLY ENJOYED THE
MUSEUM BUT TODAY
WAS EXHAUSTING.



I WANT TO BE INDEPENDENT
AND TRAVEL ALONE BUT I FEEL
ANXIOUS EVEN WHEN I'VE PLANNED
THE TRIP IN ADVANCE.

IT'S OFTEN THE LITTLE THINGS
THAT MAKE A DIFFERENCE -
USUALLY PEOPLE BEING KIND AND
HELPFUL. I'VE GOT SOME IDEAS
TO HELP MAKE JOURNEYS EASIER...

THE END



What we did and Who was involved...

In late 2018 the Dementia Services Development Trust agreed to fund the development of a comic as part of its Disruption Challenge competition.

In early 2019, Andy Hyde (Go Upstream) and Phillip Vaughan (Senior Lecturer & Programme Director, Masters in Comics and Graphic Novels, University of Dundee) developed the idea further. We chose to work in Dundee because it represents the heart of Scotland's comic creativity, activity and history.

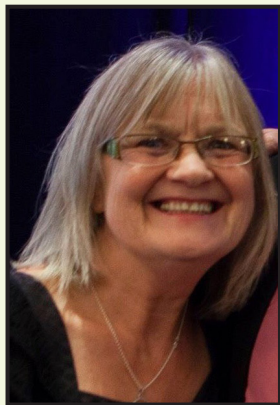
Go Upstream and The University of Dundee worked with V&A Dundee to host an initial gathering in March 2019. This attracted academics, experts in comic artwork and development, people with dementia, local city development staff and students. We used the gathering to present the project idea along with some context about the use of comics in health and wellbeing. We also did some sketching to illustrate the use of art in portraying emotion.

Following the event, Ashling Larkin and Megan Sinclair, artists and graduates of the University of Dundee Masters in Comics and Graphic Novels course met with James Mckillop, who lives with dementia, to think about how we could capture experiences and create artwork from journeys. Along with James, we were joined by Agnes Houston and Martin Robertson who also live with dementia.



Martin Robertson

“I am 61, with Posterior Cortical Atrophy, (as was Terry Pratchett, hence the hat!). This means my senses (sight and hearing in particular) become easily overloaded. Bright colours, Muzak, or confusing visions such as mirrors in the wrong place throw me. My long vision is nearly non-existent so signage is confusing unless very clear, I am registered visually impaired so can relate to how those with no sight cope or not as the case maybe. I thought the comic showed my inability to cope with sensory overload very well.”



Agnes Houston

“I am a dementia activist, diagnosed with younger onset Alzheimer’s Disease in 2006 at the age of 57. I campaign for best practice improving the lives of people with dementia, especially those experiencing sensory issues. I am a former Chair of the Scottish Dementia Working Group, former Vice Chair of the European Dementia Working Group and a former board member of Dementia Alliance International. In 2016 I was awarded a Churchill Fellowship which enabled me to travel to Canada and Ireland to seek examples of best practice relating to sensory challenges and dementia.

Being able to travel independently is so important to me and I am interested to see how we can use comics to describe our experiences. We need different ways to help people to understand the challenges we face and how they can support us to keep getting out and about.”

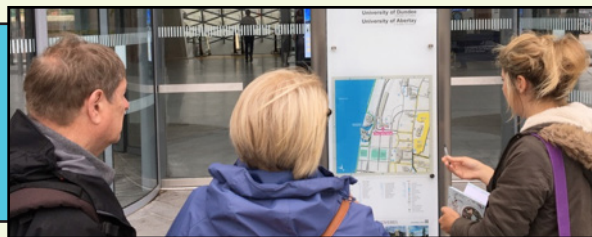


James McKillop

“After a diagnosis of Vascular Dementia in 1999, I stayed at home fearful of what people would say. After support to get back out in the community, I began to understand that, despite vascular dementia, I was still a person. I realised that I would be able to help others, by talking openly, to cope with a devastating illness. This meant having to travel far and wide, and this presented new difficulties. That is why I got involved with Go Upstream and this project, to pass on my experiences. To make life easier for others, and avoid the pitfalls.”

DRAWING FROM OUR EXPERIENCE

STORIES OF TRAVELLING WITH DEMENTIA



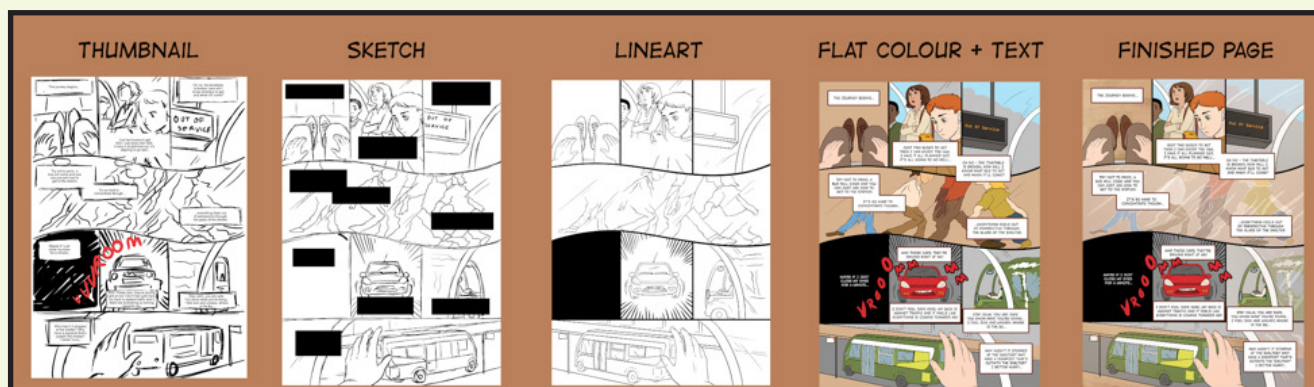
In June 2019, Andy, Ashling and Megan spent a day travelling around Dundee with Agnes, James and Martin. The group was supported by Maureen McKillop, Go Upstream intern Emma Lawson and volunteers Anna Hyde and Rosie Kenneally. We travelled in groups from the rail station, to the city centre and then to V&A Dundee where we compared notes and discussed our experiences. We took pictures, made notes and sketches.

Ashling and Megan then developed the stories and artwork in association with Agnes, James and Martin. We checked in with the group to ensure that we were creating an accurate portrayal of the experience.

In choosing a name for the comic, the project name gathered an extra word which nicely describes the representation we are trying to achieve - Drawing from Our Experience. This became the comic title.

The creative process

We learned about the various stages of creating the story and artwork and how accessible they were for the group. Initial sketches were too 'rough' and needed more definition. Some colours in the later stages were too bright and distracting. We began to wonder if black and white lineart was a useful format to use - some people with dementia might find it easier to read? We need to test this further.



An important part of the project was to learn how we can work together to create comics that truly represent some experiences of travelling with dementia. Andy, Agnes, Martin and James began to understand the artistic process, while Megan and Ashling began to understand the challenges of traveling with dementia and how to express this through their work.

Here are some of the key things that we learned:

- The stories we created focus on the challenges of travel. In the future we will begin to suggest ideas for better journeys too.
- Black and white artwork might be more accessible for some people living with dementia. What do you think?
- Sometimes pictures are better than words. We took many of the words out of the first draft.
- We chose to use the comic font for the story - it uses capital letters. We thought it might be difficult to read but found it easier than expected. What do you think?
- There are a number of audiences for this work - people affected by dementia, service providers, fellow travellers. We might need to think about telling stories from different points of view in the future...

Thanks

We would like to thank the following people:

- The Dementia Services Development Trust for their support and funding
- Agnes, Martin and James for sharing their expertise and experiences.
- V&A Dundee for generously hosting the initial workshop and supporting the project throughout (your staff were so supportive during our various visits)
- Emma, Anna and Rosie for their commitment, ideas and energy!
- Megan Sinclair and Ashling Larking for the creative content.
- Phillip Vaughan, Chris Murray and Golnar Nabizadeh at the University of Dundee.

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Dementia Services Development Trust

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The Scottish Centre for Comics Studies (SCCS) leads a research project on the use of comics for educational purposes. It has, in collaboration with various private, public and third sector partners, and working with other researchers, produced comics that communicate the findings of research, or engage the public with important issues related to healthcare, science communication, and social justice. We are proud to be working with Go Upstream in the production of this comic.

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